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ABSTRACT

As a result of federal law Public Law 99-457, Illinois has the opportunity to provide early intervention for at-risk children up to 3 years of age. These children have developmental delays, such as cerebral palsy, or are cocaine or alcohol babies. The legislative history and current status of Public Law 99-457 as it relates to the planning of early intervention services in Illinois is discussed. The document then describes ways in which a comprehensive Illinois system of early intervention services might work for families in accordance with Public Law 99-457. Recommendations and rationales for establishing such an early intervention system in Illinois are posited around three critical decision areas. These areas are: (1) eligibility, which defines which children will have a legal right to early intervention; (2) structure at the community and local level, which defines the ways in which eligible children will be found and served; and (3) finance, which defines what Illinois will pay for an early intervention mandate. (BB)

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Babies Won't Wait

Early Intervention Challenges Illinois

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Babies Won't Wait

Early Intervention Challenges Illinois

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Part One

INTRODUCTION

The American Dream is alive. Every year it brings thousands of immigrants to our country from all over the world. Foolish people think that the American Dream is only about accumulating material things. But in truth the American Dream is simply the opportunity for a person to achieve their full potential as a unique individual.

This paper is about a special set of Illinois immigrants who come by the thousands every year. These immigrants arrive by birth rather than by boat, plane, or train. All immigrants face challenges in a new land, but these youngest face special challenges between birth and age three. Some of these children have well-known disabilities such as cerebral palsy. Some of them were harmed before birth by cocaine or alcohol. Some of them were simply born into a combination of life circumstances so bleak as to actually delay their normal development. Whatever their condition, each of them has a claim to the American Dream - a chance to fulfill their potential.

Thanks to a farsighted federal law, Public Law 99-457, Illinois has the opportunity to choose to give these children their chance. That opportunity is called early intervention and Illinois already knows how to make it work. For the purposes of this paper, VIC is using the term "early intervention" to refer specifically to the combined skills in early childhood development, therapy, education, and social services directly related to P.L. 99-457.

The evidence is absolutely clear that early intervention works for these children. Science and medicine have shown conclusively that the sooner society responds to help them meet their special challenges the greater the positive human outcome. Make no mistake about it, Illinois will have to respond to these tiny immigrants sooner or later. The longer Illinois waits, the higher the cost will be in dollars and in the unforgivable loss of human potential.

To some readers of this paper the term "early intervention" may be unfamiliar, or seem to suggest mysterious, high-technology medical procedures. VIC apologizes if any of the terminology used here seems off-putting, but there is nothing esoteric about early intervention. At bottom, all we mean here by "early intervention" is the practical

coordination of whatever techniques are necessary to help an individual child and family to strive for their full development.

There are no categorical early intervention services. There is no single right way to "treat" all children with cerebral palsy, or all cocaine babies. The heart of early intervention has three elements: family participation, a written individualized plan, and a person whose job it is to make certain that the plan is carried out and the family is involved. Each of these three elements will play out differently for different families.

Family participation will vary, but early intervention recognizes that all families have some strengths and that these strengths can be nurtured. The written plan, formally called an Individual Family Service Plan or IFSP, will be approved by the family. It can be thought of as a covenant between the child and family and the wider community, the purpose of which is to provide efficiently for the developmental needs of the child and to enhance the capability of the family. The person who is responsible for the IFSP is formally called a "case manager", but is best thought of as a tour guide (selected by the family) who helps the family negotiate the system.

Surrounding the heart of early intervention is the whole range of possible developmental services: physical therapy, psychological help, speech/language therapy, and so forth. They are provided through the family's individual plan. Therefore an individual plan for a child deemed to be at risk of substantial delay might call for simply a monthly visit to the home by a child development specialist and regularly scheduled group meetings for the parents. On the other hand, an individual plan for a child facing the severe challenges posed by some forms of cerebral palsy might coordinate an intricate series of physical, speech/language, and other therapies within the context of the child's ongoing formal medical treatment.

Today Illinois doesn't provide the practical early intervention families need because our services are fragmented and incomplete. That denies these children their birthright and robs society of their future contributions. Illinois can choose to change that in the coming year. Valuable work has already been done by many to mark the path ahead. In writing this paper VIC hopes to contribute to a wide ranging discussion as the General Assembly's Special Joint Committee carries out its work, and as the formal discussion of an Illinois mandate for early intervention begins.

Part Two

SUMMARY OF VIC RECOMMENDATIONS FOR EARLY INTERVENTION IN ILLINOIS

The case for each of these recommendations can be found in Part 6 between pages ten and eighteen.

RECOMMENDATIONS ON ELIGIBILITY

1) The 1991 Illinois General Assembly should establish a legal right to early intervention services for all eligible children.

2) Illinois should adopt the State Interagency Council on Early Intervention's definition of developmental delay to ensure that all such children are eligible.

3) Illinois should include in the required definition of high probability risk conditions children exposed to drugs before birth to ensure that all such children are evaluated for eligibility.

4) Illinois should give children at risk of substantial developmental delays the legal right to early intervention services.

5) Illinois should define substantial risk as the presence of three specific risk factors[1] plus the judgement of the interdisciplinary evaluation team.

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[1] **For example: 1) Family history of developmental disability, 2) Mother who is under 18, and 3) Inadequate prenatal care when combined with the professional judgement of the evaluation team would make the child and family eligible for in Individual Family Service Plan. See Appendix B for a possible list of risk factors.**

RECOMMENDATIONS ON LOCAL SERVICE STRUCTURE

6) Illinois should define the boundaries of the local structure of the early intervention system so that they coincide with existing political and geographic boundaries.

7) Illinois should give the new local coordinating councils responsibility and sufficient resources for the creation of formal local referral networks as the primary entry points for families.

8) Illinois should give the new local coordinating councils primary responsibility and sufficient resources for conducting local child find and public awareness efforts.

9) Illinois should insure that local child find efforts provide for the screening of children who have been found to be physically or sexually abused.

RECOMMENDATIONS ON FINANCE

10) Illinois should write its Medicaid rules, as permitted by federal law, to provide that all early intervention services listed in an Individual Family Service Plan will be covered by Medicaid for Medicaid-eligible children.

12) Illinois should create an advisory council to the lead early intervention agency on coordinating private charitable early intervention funds.

13) The Governor should create a special task force to report to the General Assembly in early 1991 on the possible use of private insurance for early intervention services.

14) Illinois should create a central billing office for early intervention within an existing state agency to ensure coordination of state spending and the maximum utilization of federal matching funds under Medicaid.

Part Three

LEGISLATIVE HISTORY

In October, 1986, President Reagan signed Public Law 99-457. This new statute is an intricate set of amendments to the 1974 landmark law, Public Law 94-142. The 1974 law guarantees a free appropriate public education to all schoolage children and thus created the system of Special Education which today enrolls about eight per cent of Illinois' students.

The 1986 law, P.L. 99-457, went beyond the earlier statute's concern for education to portray a wide vision of immediate effective societal response to the risk or presence of mental, communicative, physical, or emotional delay in the first three years of life. Specifically, P.L. 99-457 offered planning funds to the individual states in return for each state's promise to create, over five years, a comprehensive system to address the full range of developmental needs of all eligible children during their first three years of life. All fifty states have accepted the federal challenge.

Each state must define eligibility by establishing a formal definition of developmental delay and a formal definition of which physical or mental conditions create a **high probability** of developmental delay. These two definitions are mandatory under the terms of P.L. 99-457. The state may also choose to establish a further optional definition of which conditions create a **substantial risk** of developmental delay. Each definition can be thought of as defining a specific set of children to be served. P.L. 99-457 clearly states that all children who meet the state's eligibility requirements must be served. The federal law further guides the state planning process by requiring fourteen mandatory components, including family participation, for the final comprehensive system.

The impetus driving Congress was a combination of the scientific consensus around the incredible rate of human development during the first years of life, and the therapeutic evidence that prompt, skilled intervention, (sometimes starting while an infant is still in the hospital) will make an enormous difference in the outcome for a child with a real or potential developmental delay. For children and families this difference translates to increased opportunity for lifetime independence and achievement. For public policy it translates to the saving of dollars which would have to be spent later for care, services, and education. For society as a whole it translates to the benefits of participating, productive,

and independent citizens. Congress has now dramatically underlined its intent by passing the 1990 Americans with Disabilities Act which further guarantees the civil rights of the one American in ten who has a disability.

Part Four

THE SITUATION TODAY

Today Illinois children have no legal right to early intervention services during their first three years of life. The lead agency for P.L. 99-457 planning[2], the Illinois State Board of Education, estimates that about **8,000 children** are receiving early intervention services through some **120 different local providers** who are guided and funded to some extent by **eight different State agencies**[3]. The widest current rough estimate of the number of eligible children is **90,000**[4].

To put it bluntly, the present system is a fragmented labyrinth which families are forced to thread in the dark in search of services for their child. Furthermore, there is no sustained effort to find families who may not know that their child needs early intervention. Despite three years of planning the State has neither a complete roster of current local providers or reliable current cost estimates[5].

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[2] A complete list of the members of P.L. 99-457 planning body, the State Interagency Council on Early Intervention, can be found in Appendix C.

[3] Official Illinois "Application for Federal Fiscal Year 1990 Funds Under Part H of the Education of the Handicapped Act", submitted to the U.S. Dept. of Education in August, 1990.

[4] Illinois Dept of Public Health estimate supplied to the Interagency Council's Finance Subcommittee on 11/14/90. This estimate is based on 1988 figures from Vital Statistics and the Adverse Pregnancy Outcome Reporting System of the Dept of Public Health. It provides unduplicated figures for biological and established risk of developmental delay and represents the most complete approximation to date of the statutory requirements of P.L. 99-457. Of the 90,000 children estimated, some 58,000 are identified as being "environmentally at risk" based on one of three single risk factors: 1) the mother is under 18, 2) the mother's birth interval was less than one year, and 3) the mother received no prenatal care. Therefore this estimate does not utilize the methodology suggested in this paper for identifying children at riskinclude children at risk of substantial developmental delay.

[5] This should not be taken as a reflection on the providers. They are some of the true unsung heroes and heroines of our day: people who routinely make miracles for families on shoestring budgets.

Nevertheless, Illinois has accepted the challenge of creating a comprehensive system, a system where children will have a right to early intervention, and has made some real progress in its planning towards that system. Task forces of the State Interagency Council have completed work on the problems of personnel, program standards, finance, and on a possible structure for a comprehensive system[6]. The possible structure has been tested and revised based on public comments and is a partial basis for the possible Illinois future described in the next section of this paper.

[6] See Appendix C for a diagram.

Part Five

HOW THE FUTURE COULD WORK FOR FAMILIES

The section in italics below is VIC's attempt to describe how a final comprehensive Illinois system of early intervention services might work for families. It is based on the language of P.L. 99-457 and its accompanying federal regulations as well as the work of the State Interagency Council on Early Intervention. The reader should pay particular attention to a) the description of the local child find network based on specific referral sources coordinated through a new local coordinating council; b) the description of how the new Individual Family Service Plan and individual case manager work to govern the family's interactions with the overall system; and c) the description of the statewide central directory which empowers families through information.

A few years from now Illinois will be able to identify and serve every family in the state, no matter where they live or what their economic circumstances, that has a child between birth and age three who falls within any one of three broad categories of eligibility.

The categories are: first, those children whose developmental disabilities and/or delays can be detected by standardized tests or professional judgement; second, those children who have physical or mental conditions which put them at high probability of delayed development; and third, those children who are found to be at substantial risk of developmental delay as determined by a combination of life conditions and professional judgement.

Illinois will find these families through a statewide child find system of trained and designated primary and secondary referral sources. The primary referral sources will cue in as closely as possible to the child's birth and will include hospitals, pediatricians, and other health care providers.

The secondary referral sources will be community based and include childcare providers, churches, social service providers, and community-specific efforts. These vital secondary referral sources will be coordinated in each community through a broad-based local coordinating council which will be made up of local health providers, education providers, public officials, state agencies, and community representatives. The local coordinating council will be organized and staffed by an independent agency.

Each designated referral source will know how to introduce the family to the diagnostic and treatment parts of the system within two days after a child is identified as potentially eligible. Coordination with the family, what is officially known as case management, will begin as soon as a child is identified to ensure that families don't fall through the cracks.

Every designated referral source will refer the family directly to their community's core early intervention provider. This core provider will determine whether or not the child is eligible for an Individual Family Service Plan or IFSP under the three broad categories of eligibility. It is important to keep in mind that "eligibility" in this case means eligibility for an IFSP rather than for any particular set of services.

The decision on eligibility and the creation of the family's specific IFSP will be the responsibility of an interdisciplinary team which must complete its work within 45 days. The team will combine health, education, and social service professionals along with the family. The team will be backed up when necessary by specialized diagnostic services.

If the team finds that the child is eligible, it then prepares an IFSP which defines in detail the who, what, when, where, and why of the child's services. The family is a full member of the team and has the final right of refusal on any and all aspects of the IFSP. A child will not be "labeled" by being found eligible for an IFSP. For children whose needs are clear, early intervention can begin immediately while the final details of the IFSP are being worked out. The core provider is then responsible for fulfilling the IFSP either directly or through contracted professional services. There will be no waiting lists.

The IFSP will be a living document which will change in tune with each individual child's first three years of life. We will see a wide variety of IFSPs. Some will simply provide for continued monitoring of the child and some basic information for the family. Others will call for specific developmental therapies. Most will begin with services in the infant's home and progress to services at designated centers. Throughout the family's experience with the Illinois early intervention system they will be assisted by a sort of tour guide, officially their case manager, who will ensure on the one hand that the family's needs are met and, on the other hand, that the family is able to participate in the system.

Whenever a child graduates from early intervention, their IFSP will define how they will transition to other community services. For those children who will need to begin special education, the IFSP will ensure that special education will begin promptly upon their third birthday. The child and family will be protected by a formal set of procedural safeguards at every stage in the early intervention process.

Family involvement will also be enhanced through the creation of a statewide central directory of early intervention services. The central directory will be accessible via telephone, computer, and mail and will be available in the family's native language. The central directory will provide specific information on early childhood development, the various causes of developmental delay, and local early intervention resources. The central directory will be able to respond promptly and specifically to parent and public inquiries.

The core provider will receive timely reimbursements for all services provided under a proper IFSP from a single Illinois state source which will then bill in turn the applicable final financial source which may be Medicaid or a particular state agency. Each part of the Illinois early intervention system, identification, assessment, and service provision will be interdependent.

Part Six

VIC'S POSITION ON THE CRITICAL TASKS AHEAD

The possible future system just discussed is obviously very different from today's reality in Illinois. It is the position of Voices for Illinois Children that Illinois should establish a birth to three system as described above through enabling legislation in 1991. In order to accomplish this we believe that there are three critical decision areas which require immediate attention:

1) The area of eligibility defining which children will have a legal right to early intervention services,

2) the area of structure at the community level defining how eligible children will be found and served, and

3) the area of finance defining how Illinois will pay for an early intervention mandate.

VIC's specific recommendations are listed in bold face following the remarks on each area.

VIC recognizes that a comprehensive system cannot be waved into existence by even the most committed of legislatures, and that a phase-in period of several years will be necessary between the passage of the mandating legislation and the complete operation of the system.

VIC RECOMMENDATION ON ESTABLISHING AN EARLY INTERVENTION SYSTEM

1) **THE 1991 ILLINOIS GENERAL ASSEMBLY SHOULD ENACT ENABLING LEGISLATION ESTABLISHING A LEGAL RIGHT TO EARLY INTERVENTION SERVICES FOR ALL ELIGIBLE CHILDREN**

Eligibility

It is worth remembering that P.L. 99-457 requires the eligibility decision to be based upon an interdisciplinary team's evaluation of each child's cognitive, physical, speech/language, psycho-social, and self-help development. Illinois must establish two definitions and may choose to establish a third. It is also important to bear in mind that we are discussing eligibility for an Individual Family Service Plan rather than for a given set of services. Depending upon the child's needs, an IFSP could call for a low, mid, or high level of early intervention services.

Each definition can be thought of as creating a specific class of eligible children. Therefore Illinois must define two mandatory classes of eligible children, and has the further option of defining a third eligible class.

The first mandatory definition is "developmental delay". All children who meet this definition will be eligible. This is the only definition which Illinois has completed in the first three years of federally-funded planning. The proposed Illinois definition states that "developmental delay" refers to: a) children with a given level of measurable delay on standardized tests and b) children who the interdisciplinary evaluation team consider to be developmentally delayed based upon their professional judgement.

VIC supports this definition based upon the definition's recognition of the primary role of professional judgement. The need for asserting professional judgement arises from the lack of any single testing instrument accurate enough to rely on as a reliable test of developmental delay. This was known to Congress in 1986 and is a large part of the reason why the federal law demands the use of an interdisciplinary team.

The second mandatory definition is "diagnosed physical or mental condition which has a **high probability** of resulting in developmental delay". All children who meet this definition will be eligible. Illinois has not completed this definition. The Early Childhood Intervention Committee of the Illinois Association of Rehabilitation Facilities has done valuable work on the eligibility questions and their conclusions, together with the VIC Building At The Frontier Report[7], have helped VIC to take the following positions.

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[7] See Appendix A for a description of VIC's involvement with early intervention.

The high probability definition will need to be authorized in the enabling legislation and defined by Illinois regulations. In addition to the more traditional conditions such as Down Syndrome, VIC believes that this definition must include children exposed in utero to cocaine and/or other controlled substances[8] and children with fetal alcohol syndrome.

The optional definition would define children who are "at risk of having substantial developmental delays" as eligible. The Illinois planning effort has to date declined to recommend the inclusion of this group of children within the comprehensive system. VIC believes that there are three compelling reasons why Illinois should bring these children within the mandate.

First, such children are most likely to respond quickly to early intervention. Second, if services are indicated for such a child they will most likely be simple and inexpensive. and Third, the inclusion of such children is an important backstop to the professional judgement of the interdisciplinary evaluation team. It acknowledges the fact that current formal evaluation instruments are still too imprecise for satisfaction and that there will be children at risk of substantial developmental delay who can not be easily diagnosed. It is vital to bear in mind that the statute refers to "substantial developmental delays" rather than simple risk.

Therefore we are not debating whether to include the one in five Illinois children who live in poverty and are often loosely referred to as being "at risk". On the contrary, the statute only asks us to decide whether to include a much smaller set of children whose level of risk is high enough to place them in danger of "substantial developmental delays" later in life. VIC is proposing that Illinois should include define the risk of substantial delay as resulting from the presence of a series of risk factors.

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[8] The Illinois Dept of Children and Family Services (DCFS), as reported in the Chicago Sun-Times newspaper on 9/21/90, has 2,400 such children currently in foster care. In 1985 only 181 such children were in foster care. DCFS further estimates that the 2,400 children represent just 20 per cent of the total population of cocaine and drug exposed infants in Illinois.

For instance, under this definition a child would be eligible for an IFSP under VIC's definition if the mother was under 18, and had not received adequate prenatal care, and if there was a family history of abuse or neglect, and if the interdisciplinary team felt it was warranted. It is VIC's opinion that once the terms of the debate are fully understood, there will be general agreement that these are likely to be the very children who will benefit the most from the lower levels of early intervention services and thus should be eligible.

The enabling legislation would authorize the setting of eligibility standards for these children by Illinois regulation. Eligibility would be defined through regulation in language similar to this: " A child shall be eligible for an IFSP when the interdisciplinary team finds the presence of three[9] or more of the following conditions[10] and then determines that, in the clinical judgement of a consensus of the team, the child is at substantial risk of developmental delay if early intervention services are not provided." The regulation would then provide a list of risk conditions.

VIC RECOMMENDATIONS ON ELIGIBILITY

1) **Illinois should adopt the state interagency council's definition of developmental delay.**
2) **The definition of high probability risk conditions should include children exposed to drugs before birth.**
3) **Children at risk of substantial developmental delays should have a legal right to early intervention services.**
4) **Substantial risk should be defined as the presence of three risk factors plus the judgement of the interdisciplinary team.**

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[9] VIC is suggesting an initial use of three risk factors. Based on actual experience of the final comprehensive system Illinois could later choose to either widen the definition by lowering the number of risk factors or narrow the definition by increasing the number of risk factors. Professional judgement must always be a part of this definition.

[10] A list of risk factors can be found in Appendix B.

Local Structure

VIC supports the broad outlines of the proposed structure as defined by the State Interagency Council: 1) The state lead agency will divide the state into regions and local community areas; 2) Each region will have a diagnostic capability; 3) Each local community area to have a core provider and a coordinating agency.

The enabling legislation must ensure that the boundary-setting exercise, defining the regions and local community areas, represents as fairly as possible Illinois' demographic diversity. The geographic boundaries must be drawn to ensure the maximum coordination with existing state and local resources. The bottom-line requirement is that the boundaries of the early intervention system must coincide with current Illinois geographic and political boundaries such as counties.

The local structure must be responsive to the problems of rural isolation as well as concentrated urban poverty. It must take into account the federal regulatory requirement making transportation a part of each IFSP. It would be foolish to create a structure which families can only reach after hours of travel, or which requires unreasonable treks by system personnel to reach client families.

The statute makes child find and public awareness mandatory components of the final comprehensive system. The proposed structure reflects the federal regulations in its call for the creation of working networks of primary and secondary referral sources linked to each local area's core early intervention provider. The operation of these networks will require the specific assignment of skilled personnel. The federal regulations require that every child be referred for evaluation within two days of identification, and that the eligibility decision be made within 45 days of referral. There can be no place for waiting lists or families falling between the cracks in the system.

The primary referral sources[11], particularly the hospitals, can operate a highly efficient post-natal screening system if one is provided for them. However the comprehensive system can not be solely based on in-hospital identification. The comprehensive system must be able to identify and evaluate children up to their third birthday, and to do that it must mobilize the community health resources of Illinois and provide them with a clear, direct link to the core early intervention provider in each respective community area.

The creation and operation of the local primary and secondary referral[12] networks must be the primary task of the new local coordinating agencies. These agencies must act as the executive arms of the local interagency councils. The local coordinating agencies will be answerable to the state lead agency[13] and they must have an adequate physical presence in the local community. The proposed structure puts the responsibility for community outreach with the new local interagency councils and the new local coordinating agency. Both must have realistic operating areas and sufficient resources to do the job. It will be the task of the new coordinating agency to create and staff the local interagency councils.

It will be the task of the local councils to create locally-sensitive child find and public awareness efforts. VIC believes it essential that children whom the Illinois Dept.of Children and Family Services has found to be physically or sexually abused be screened for possible eligibility. The enabling legislation should provide for the creation of the local councils with the resources through the local coordinating agency to create and train the primary and secondary referral sources, conduct community child find campaigns, and conduct local public awareness campaigns.

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[11] Parents, hospitals, pediatricians, public health clinics, infant mortality reduction programs, early intervention providers, and licensed child care providers are examples of primary referral sources.

[12] Examples of secondary referral sources would include relatives, local churches, and community child screening programs.

[13] Either directly or to another state agency if so prescribed by the statewide master interagency agreements or the enabling legislation.

VIC RECOMMENDATIONS ON LOCAL STRUCTURE

1) **The boundaries of the local structure should coincide with existing political and geographic boundaries.**

2) **The new local coordinating councils should have primary responsibility and sufficient resources for the creation of formal local referral networks.**

3) **All children who have been found to be physically or sexually abused according to the Dept of Children and Family Services should be screened for possible eligibility.**

4) **The new local coordinating councils should have primary responsibility and sufficient resources for conducting local child find and public awareness efforts.**

Finance

The Illinois early intervention system will need a strong financial base. That base should include the following: a) all current state spending for early intervention, b) full utilization of the expanded Medicaid Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), c) the coordination of current private, primarily charitable, early intervention spending, d) new dollars from the Illinois General Revenue Fund, and e) payment for early intervention services by private health insurers without prejudice to the rights of families.

One consequence of the current fragmentation of effort is that after three years of federally funded planning the State Interagency Council still does not know how much Illinois currently spends on early intervention. The enabling legislation must require the disclosure of this information to whatever state agency it designates as lead agency.

In 1989 Congress made major changes in the scope of the EPSDT program. In Illinois this program is run by the Dept. of Public Aid and known as Healthy Kids. Previously the Illinois threshold for Healthy Kids was 100 % of the poverty level. As of April, 1990, the new level is 133 % of the poverty level, which means that an Illinois family of four with an annual income of $ 16,000 is now eligible for every child under age six.

Full utilization of EPSDT, as estimated by the federally-supported National Early Childhood Technical Assistance Center, would pay for 90 per cent of all early intervention services for 30 - 50 per cent of all eligible children[14]. To take advantage of the EPSDT changes, the enabling legislation should follow the recent example of Louisiana and stipulate that all services prescribed by a properly written Individual Family Service Plan will be deemed EPSDT eligible.

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[14] "The Role of Medicaid and EPSDT In Financing Early Intervention and Preschool Special Education Services" Report of Fox Health Policy Consultants, Inc, April, 1990

Illinois needs to recognize the vital creative role that private charitable funds and community volunteers have long played in early intervention services. These efforts must continue and expand under the comprehensive system if it is to succeed. The enabling legislation should therefore require the appointment of an ongoing advisory committee on private birth to three resources to the state lead agency. This committee would provide an additional avenue for input by private providers and supporters of early intervention as well as a mechanism for encouraging their participation in the local interagency councils.

It is inevitable that some new state spending will be necessary for the creation and operation of a comprehensive early intervention system. The new local coordinating councils, local coordinating agencies, the referral networks, the program standards for the comprehensive system, the personnel development requirements of the comprehensive system, as well as the full range of services necessary for the IFSPs, will all, to some extent, require new dollars. Wherever possible these needs should be met by the wise coordination of current resources, but it is inevitable that new spending will be necessary. These dollars will pay for themselves many times over in subsequent year's savings in special education and other costs.

The question of private health insurance must be approached with sensitivity[15]. Most Illinois families are covered by some kind of health insurance[16]. Early intervention can save money over the mid to long range for private insurers as well as government. It seems reasonable at this time to expect private insurers to assume their fair share of the costs. However, private insurance cannot be utilized in any way that would jeopardize the other health insurance needs of families. The Governor should create a special committee of legislators, parents, state agencies, insurers, the state insurance department, and private citizens to study the question and report back to the General Assembly with specific recommendations in early 1991.

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[15] "Medicaid and Other Third-Party Payments: One Piece of the Early Intervention Financing Puzzle", the Association for the Care of Children's Health, Bethesda, MD, to be released in late 1990.

[16] A U.S. Census Bureau survey during 1986-1988 found that 76 % of all Americans had some health insurance. The figures for Black and Hispanic citizens were 62 % and 48 % respectively. Source: Wall Street Journal, 7/12/90, page B 1.

Finally, the enabling legislation should create a new office within an existing state department to act as the central billing agent for the comprehensive early intervention system. This office would operate on a "pay and chase" basis, issuing timely payments to the core providers and then billing whatever sources were most appropriate. Maine has recently created just such an office as a way to improve interagency coordination, maximize their EPSDT share by "capturing" all public early intervention spending, and provide timely payments to providers[17].

VIC RECOMMENDATIONS FOR FINANCE

1) **THE ILLINOIS DEPT OF PUBLIC AID SHOULD WRITE MEDICAID RULES PROVIDING THAT ALL EARLY INTERVENTION SERVICES LISTED IN AN IFSP WILL BE COVERED BY MEDICAID FOR MEDICAID-ELIGIBLE CHILDREN.**

2) **THE ENABLING LEGISLATION SHOULD CREATE AN ADVISORY COMMITTEE TO THE LEAD AGENCY ON COORDINATING PRIVATE CHARITABLE EARLY INTERVENTION FUNDS.**

3) **THE GOVERNOR SHOULD CREATE A SPECIAL TASK FORCE TO REPORT TO THE GENERAL ASSEMBLY IN EARLY 1991 ON THE POSSIBLE USE OF PRIVATE INSURANCE FOR EARLY INTERVENTION SERVICES.**

4) **THE ENABLING LEGISLATION SHOULD CREATE A CENTRAL BILLING OFFICE FOR EARLY INTERVENTION WITHIN AN EXISTING STATE AGENCY.**

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[17] Workshop presentation by Susan Mackey-Andrews, Executive Director of Child Development Services for the Maine Interagency Coordinating Council, at the U.S. Dept of Education's Partnerships For Progress IV Conference, Arlington, VA, 7/30/90-8/1/90.

Part Seven

CONCLUSION

In calling for immediate action on eligibility, structure, and finance VIC does not mean to slight the many other needs of a comprehensive system such as personnel development, program standards, or procedural safeguards[18]. It is VIC's position that these areas will come into clearer focus once the enabling legislation settles the questions of eligibility, local structure, and finance.

[18] These questions are discussed in the VIC Special Report "Building At The Frontier: Policy Choices for Young Children At Risk" published in March, 1990.

Appendix A: A SUMMARY OF VIC'S INVOLVEMENT WITH EARLY INTERVENTION

In 1987 a distinguished group of private Illinois citizens published "The Plan of Action for Children" which both created Voices for Illinois Children and provided it with an underlying philosophy. That philosophy argued that any major future initiative on behalf of Illinois children and families must be judged on five principles: Will it be comprehensive ?, Will it be accessible ?, Will it provide for continuity ?, Will it be accountable ?, and Will it be universally available to all who are eligible ?.

VIC was struck by how harmoniously Congress seemed to have woven these principles into Public Law 99-457. VIC's involvement began with a formal Comment in early 1988 on the proposed federal regulations. In March of 1988 VIC started regular monitoring and reporting on the Illinois planning process. VIC attended the first meeting of the Illinois Interagency Coordinating Council and every subsequent meeting. In addition to the formal Council sessions, VIC has attended most of the ad hoc committee meetings, the public hearings which have been held pursuant to Illinois' applications for continued federal funding, and the public comment sessions on a proposed structure for a comprehensive Illinois birth to three system. The 7,000 readers of VIC's quarterly newsletter have seen three stories about Illinois' involvement with P.L. 99-457 and VIC has developed a special early intervention mailing list of over 1,000 people. VIC has issued three previous papers related to P.L. 99-457: an analysis and response to the 1989 Illinois Application in June, 1989; a comparison and response to the federal regulations and the 1989 Illinois Application in September, 1989; and a summary and response to the proposed structure for a statewide system in April, 1990.

In 1989 VIC joined with the Chicago Community Trust for an 18 month process called Building At The Frontier. Building At The Frontier was an effort to delineate Illinois' policy choices for young children between birth and age five who are at risk from whatever cause.

The high point of this process came in September, 1989 with the Building At The Frontier conference in Rockford. For three days a selected group of 125 people representing parents, state agencies, service providers, higher education, policy makers, communities, and advocates participated in a series of intense small group discussions. Each participant was assigned to a specific working group.

Each group developed a set of recommendations and after further analysis and comment VIC published these recommendations in March, 1990 as the Building At The Frontier Report. That report forms the direct base for this paper. Among other things, the Building At The Frontier Report called on the Illinois General Assembly to create a special committee to analyze early intervention issues, thus foreshadowing the creation of the current Special Joint Committee.

VIC began a new phase of early intervention activities in July, 1990. This phase will focus on building a wider public understanding of the issues at stake in the possible creation of a new system of early intervention services. Part of this work will be supported by a three year Priority Grant from the Chicago United Way to monitor and facilitate early intervention planning in Chicago.

The heightened pace as Illinois starts its fourth year of formal planning, the upcoming activity of the Special Joint Committee of the General Assembly, and the inevitability of a new state Administration in 1991, has led VIC to conclude that this is the right time to set forth some cardinal elements for the coming debate on what Illinois ought to do to transform today's fragmented and discontinuous system of early intervention services into the comprehensive, coordinated, family-centered system demanded by federal law.

APPENDIX B: POSSIBLE LIST OF RISK FACTORS FOR A DEFINITION OF "AT RISK OF SUBSTANTIAL DEVELOPMENTAL DELAYS"

a: Admission to an Neonatal Intensive Care Unit

b: Family history of developmental disability, developmental delay, or severe emotional disturbance

c: Family history of abuse or neglect

d: Family history of alcohol or substance abuse

e: Family history of genetically transmissible conditions known to cause developmental delay

f: Alcohol or substance abuse by the mother during pregnancy

g: Parental history of developmental disability

h: Parental history of severe emotional disturbance

i: Homelessness

j: Child is a ward of the state

k: Mother had a transmissible disease known to cause developmental delay during pregnancy

l: Mother less than 18 years of age

m: Inadequate prenatal care

n: Mother took medication known to pose a risk of developmental delay during pregnancy.

In order to be deemed eligible for early intervention services, the interdisciplinary team would have to find the presence of three or more of the above risk factors and make a professional judgement that the child is in need of early intervention services. This decision would lead to the creation of an Individual Family Service Plan for the child.

APPENDIX C: THE STATE INTERAGENCY COUNCIL ON EARLY INTERVENTION

P.L. 99-457 requires participating states to designate a lead state agency and to create an interagency planning council representing the state agencies involved with early intervention, local early intervention providers, parents, the legislature, and early intervention education and training. Illinois Governor James Thompson designated the Illinois State Board of Education as lead agency and created the State Interagency Council on Early Intervention by Executive Order.

1) Current Members of the Interagency Council

STATE AGENCY REPRESENTATIVES (9)[19]

State Board of Education: Gail Leiberman - Council Chairperson
Dept. of Mental Health and Developmental Disabilities: Lynn Handy
Division of Services to Crippled Children: Wanda Thompson
Planning Council on Developmental Disability: Cathy Ficker-Terrill
Dept. of Public Aid: Stephen Spence
Dept. of Alcohol and Substance Abuse: Alvera Stern
Dept. of Children and Family Services: Sue Howell
Dept. of Rehabilitation Services: Carl Suter
Dept. of Public Health: Dr Stephen Saunders

LEGISLATIVE REPRESENTATIVE

House Minority Leader Lee Daniel's Office: Race Davies

PERSONNEL TRAINING REPRESENTATIVE

Jeanette McCollum - University of Illinois at Urbana/Champaign

EARLY INTERVENTION PROVIDER REPRESENTATIVES (3)

Vincent Allocco - El Valor Inc, Chicago
Maureen Patrick - Family Focus, Evanston
Betsy Voss-Lease - South Metropolitan Association, Flossmoor

[19] Each of these agencies has some current responsibility for early intervention.

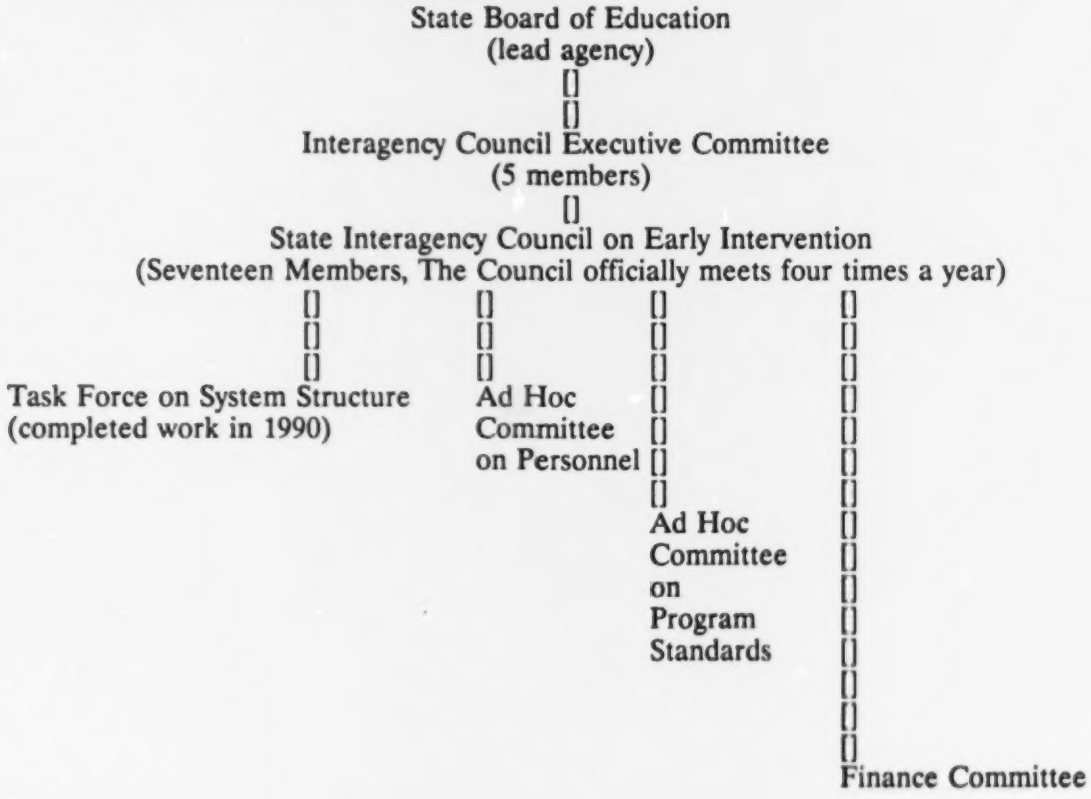
PARENT REPRESENTATIVES (3)

Susan Walter, Highland

Linda Colson-Perlstein, Glen Ellyn

_____, (Vacant since March, 1988. Gov. Thompson has never named the third parent representative to the Interagency Council)

2) Structure of the State Interagency Council



NOTE: The Task Force and Committee memberships include both members and non-members of the Interagency Council.